

# The PREVENTION CONNECTION

—It is easier to build a child than to repair an adult—

## Disability, Health and Wellness

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**A**s many as 51 million people with disabilities live in the United States. About 25 million of them have a severe disability. Despite the emphasis our society has placed on health promotion and prevention during the last twenty-five years, until recently, the words “disability,” “health” and “wellness” were seldom heard in the same sentence. Disability has long been viewed from a sickness model—once disabled, always ill and in need of medical care. But in 1986, as part of a decade-long movement by people with disabilities, the National Council on Disability established as a national goal the prevention of secondary conditions experienced by people with

disabilities. This goal stated that people with disabilities could lead healthy and independent lives, and that one of the means was through access to health promotion and wellness strategies.

### Disability and Health in Montana

**We estimate that there are as many as 120,000 Montanans with at least one chronic or permanent impairment and that about 27,000 experience severe disability.**

*Continued on Page 3*

### Glossary

The terms **disability**, **severe disability**, and **secondary conditions** have many interpretations.

- For our purposes, “disability” means limitation due to a physical or cognitive impairment. The Americans with Disabilities Act (ADA) considers a person to have a disability if the person has a physical or mental impairment that substantially limits one or more of the major life activities, has a record of such an impairment, or would be regarded as having such an impairment.
- “Severe disability” means someone is unable to perform one or more activities, has one or more specific impairments (e.g., spinal cord injury), uses a wheelchair, or is a long-term user of crutches, canes, or a walker.
- “Secondary conditions” are health-related conditions that occur after a person has a disability and for which individuals are at significantly increased risk because of their impairment. Two examples are decubitus ulcers (pressure sores) for people who use wheelchairs and, for many people who acquire a disability, isolation, fatigue and depression. Treatment for decubitus ulcers can cost well over \$90,000 per case.

### disABILITY

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## *disABILITY*

by Vicki Turner, Co-Coordinator  
Prevention Resource Center

**H**aving worked in the disability field for thirteen years, I've come to realize that each of us is only temporarily able-bodied and that disability is a natural part of human life. This has been my personal as well as my professional experience. My family is filled with people who have disabilities. For the most part, we are no different than any other family: as any family does, we accept one another's strengths and challenges. My aging mother is living with Parkinson's. My husband, the youngest of seven children, has three older siblings who have developmental disabilities, and even though my brothers-in-law benefit from services provided by the developmental disabilities system, we are the primary caretakers. Though it has its rewards, the responsibility can be exhausting.

Disability issues have real implications for prevention. Families who have a member with a disability are at increased risk of abuse, neglect, alcohol and sub-

stance abuse, and divorce. The high school dropout rate is much higher for youth with disabilities than it is for the general population.

Currently there are approximately 51 million people in the United States who have a disability. Many are living at or below poverty level, for even though many people who have disabilities want to work, there have traditionally been disincentives effectively preventing them from doing so. Fortunately, on December 17, 1999, a landmark piece of federal legislation, the Workforce Incentives Improvement Act, was passed, allowing people with disabilities to work while retaining their Medicaid and public health care coverage. *(For more information, please see the article below.)*

Since coming to the Prevention Resource Center, I've noticed similarities between the disability and prevention movements. Both help youth build confidence and pride. Both are attempting to bring about 'systems change' through societal and cultural shifts, with an ultimate goal of making the world a better place to live. We hope this article will contribute to meeting that goal.

*Vicki & Jan*

## *Removing Barriers to Employment*

**T**he unemployment rate among working-age adults with severe disabilities is nearly 75%, partly because outdated institutional barriers limit their opportunities to work. Under current law, people with disabilities can become ineligible for Medicaid or Medicare if they work, forcing them to choose between health care coverage and employment. The Ticket to Work and Work Incentives Improvement Act of 1999, signed by President Clinton in December, will break down these barriers by:

- Creating new options and incentives for states to offer a Medicaid buy-in for workers with disabilities;
- Extending Medicare coverage for people on disability insurance who return to work;

- Creating a \$250 million Medicaid buy-in demonstration to help people whose disability is not yet so severe that they cannot work; and
- Enhancing employment-related services for people with disabilities through the new Ticket to Work Program.

*"Today, we say with a simple, but clear voice, no one should have to choose between taking a job and having health care."*

President Bill Clinton  
December 17, 1999

**Source:**

*Justice for All Alerts:* "President Clinton: Boosting Employment of People with Disabilities"  
<http://www.jfanow.org>

## Disability, Health and Wellness

*Continued from cover*

At the University of Montana, we have been researching health and wellness for people with disabilities since 1988. Early on, we worked closely with the Bureau of Behavioral Health of the Montana Department of Health to develop a surveillance system through which to assess the health status of adults with mobility-related impairments in Montana. We found that adults with mobility-related disabilities (e.g., spinal cord injuries, multiple sclerosis) reported experiencing an average of *fourteen* secondary conditions annually, most of which were preventable or manageable.

Through careful analysis of this information—as well as data collected since—we have developed and tested a health promotion program called *Living Well with a Disability*. Initial evaluations of the program showed that, on average, participants' health as measured by secondary conditions improved by 37% and use of medical services decreased by 45%. Anecdotally, participants also reported achieving personal goals that had long eluded them, including securing employment, moving, and dating. At present we are conducting more rigorously controlled "community trials" of more than 200 participants in nine states. Preliminary data are similar to that gathered during our earlier work.

### Preventing Secondary Conditions

Based on our success in working with adults with disabilities related to mobility impairments—and with initial support from the Developmental Disability Planning and Advisory Council—we began extending our research to include adults with developmental disabilities. Working closely with providers and people with disabilities, we developed a secondary conditions surveillance instrument designed to assess the degree of limitation from a range of secondary conditions, risk factors for secondary conditions, and medical service utilization. We are just now completing our first statewide assessment of adults with developmental disabilities served by the State's community support system. Preliminary data suggests, not surprisingly, that those who lead a more sedentary life experience greater limitations due to secondary conditions than do those who are more active. Perhaps more surprising, however, is a finding suggesting that people living in urban areas experience more health problems than those living in rural areas. Also surprising is the finding that turnover of personal assistants or direct care workers is a significant risk factor for injuries. Further, the

difference in the costs of medical services for those who experience this kind of turnover are significant.

### The Future of Disability: Health and Wellness

The paradigm of health, wellness, and prevention of secondary conditions experienced by people with disabilities is extremely productive and provocative. We have begun to broaden the application of the *Living Well Program* to include a larger population of people with disabilities. Our *New Directions Program* includes individuals of differing ages; as part of this effort, we are integrating more specific activities, including structured physical fitness. We are also exploring ways in which we can collaborate with more community providers on this effort.

One area of future research that we hope to pursue involves the relationship between health and employment. We believe that some people with disabilities, who are receiving services from the State Vocational Rehabilitation, may have secondary conditions that interfere with their ability to find and keep work. Programs designed to address this concern might improve the effectiveness of vocational rehabilitation services overall.

Finally, the new revision of the International Classification of Impairments, Diseases, and Handicaps (ICIDH - 2) is redefining our technical understanding of disability. This work is shifting the view of disability as stemming from physical or cognitive limitations toward examining limitations on participation imposed by inhospitable or inaccessible environments. We see this trend as hopeful and promising. It suggests that we should be considering the *health* implications of community development. It also suggests a vision of designing and managing our communities in such a way that health and participation are maximized for everyone. It's a great vision to take into the 21<sup>st</sup> century.

Our hope is that this vision will be furthered through the efforts described in this article, and that system-wide solutions will be developed—both to reduce health-care costs and to improve quality of life for those we serve. We also hope that Montana will pursue the development of a state-based program for disability and health in the future. Such a capacity would enable those addressing these issues to come together in their common efforts. Δ

*For more information on these and other innovative programs, visit our web site at <http://ruralinstitute.umt.edu/rtrc/rural/>*

### The Rural Institute

*The Rural Institute is part of the national network of programs funded by the Administration on Developmental Disabilities, and is committed to assisting in the provision of interdisciplinary training, research, service demonstration programs, leverage of funds, and information dissemination which increases and supports the independence, productivity, and inclusion into the community of persons with developmental disabilities. The Rural Institute currently administers 40+ projects that address the federal University Affiliated Program mission for all age ranges and in multiple areas. Areas addressed include, but aren't limited to: Rural Rehabilitation, Aging, Inclusive Schools, Transition from School to Adult Life, Social Security Work Incentives, Family and Consumer Involvement, Rural Bioethics, Hearing Conservation, Early Intervention, Personnel Preparation, Assistive Technology, Health Promotion and Health Maintenance, Supported Employment, and Montana Careers for Individuals with Disabilities. For more information, contact:*

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# Notes From the Edge:

## *Through a Mother's Eyes*

by Jan Spiegle Stinger

In 1998, Federal legislation designated the Centers for Disease Control and Prevention as the lead agency in the effort to prevent secondary conditions in people with disabilities. Public health immediately took on a new and significant role in disability and rehabilitation, particularly in terms of research and service. The Office on Disability and Health was established as part of the Centers for Environmental Health. Over the past decade, this program has made significant contributions to the development of the disability and rehabilitation field. Most recently, they took the lead in developing a separate chapter targeting disability with thirteen specific objectives as part of Healthy People 2010. Disability is also cross-listed with nearly 200 other objectives in HP 2010. Additionally, CDC established several state-based disability and health programs and funded research designed to further the development of state efforts. For more information, check <http://www.cdc.gov/nceh/programs/cddh/schome.htm>



**A**nother mother once wrote about the experience of having a child with a disability by comparing it to a vacation during which you end up at an unplanned destination. Instead of going to Italy, where you had planned to visit the Coliseum and Michelangelo's David, you wind up in Holland. It's difficult to see the beauty of tulips when your dreams of seeing the Sistine Chapel have just been shattered. While experiencing the grief of *what was supposed to be*, it's hard to appreciate the treasure of *what is*.

Emily Pearl Kingsley was the mother who captured the thoughts and feelings of the mothers of disabled children in her eloquent essay, *A Trip to Holland*. She, like all parents of children who have special needs, came to understand the very real blessings that come with parenting a child who is not "normal" by society's standards. She, like many of us who have taken this unexpected journey, came to believe it is a trip worth taking. A part of each of us will probably always wonder what might have been, but spending our lives pondering *what if* leaves little time to discover and appreciate *what is*.

When I think about what life might have been without the fact of my daughter's disability, I am awed at the impact she has had. Like Emily Kingsley, I have traveled a path I would never have willingly chosen. Like her, I searched for the why when Sara was born. I ranted at the heavens for shattering my dream of a perfect child, one who would not need apnea monitors and myriad doctors, special education and therapist's services, as well as my own never-ending advocacy and vigilance. It took quite some time and fierce soul searching to realize that Sara is perfect, just the way she is. This journey has, in fact, been so blessed and enriching, it is impossible now to think of life on other terms. Is it a coincidence that I ended up helping design and deliver services that help families like my own? Probably not.

Along the steep and varied pathways families like mine walk are many realizations that come with the daily challenge of being who we are and doing what we do. Most who walk that path learn the importance of community, the absolute truth in that hackneyed phrase, "It takes a village to raise a child." In and of itself, having a child with a disability is an isolating experience, one which takes you outside the norm. It robs you of your sense of belonging. Because few families have experienced what you are go-

ing through, it becomes difficult to identify with others. For at least a while, you lose community. Ironically, community is what families of children with disabilities may need the most.

Raising any child is a difficult challenge, but raising a child with a disability is simply not something you can do alone. It is a humbling experience to recognize the fact that you need and depend upon the help of family, friends, and the community. For some of us, admitting we need help is tantamount to failure. All of us like to believe that we are capable of meeting any of life's challenges, that tightening our belts and pulling up our boot straps will somehow set things right. But the fact is that all of us need the help of others in one way or another as we make our way through life. Having family, friends, and society around us to support us during good times and bad is what community means. It is that sense of belonging to a larger community that brings us the wisdom to recognize that asking for help is actually a sign of strength. Providing a day's worth of child care for a desperate, sleep-deprived mother, making a casserole that a father needs only to heat for his family's dinner, pounding nails for a house that will shelter a family, painting a fence while you talk with an elderly neighbor—these are the gestures which actually make a difference. Belonging to community means that what you need is much less important than what you give.

Programs like Montana's Food Bank Network, Habitat for Humanity, Lifespan Respite, Big Brothers Big Sisters, Retired and Senior Volunteers, the Peace Corps, VISTA, Hospice, Red Cross and the hundreds of other programs that provide for basic human needs without robbing a person of respect and dignity are the best form of prevention we have. They attack the isolation and helplessness that lead to substance abuse, domestic violence, and more. Random (and not so random) acts of kindness do have power.

Some Eastern religious philosophies view children and adults with disabilities as teachers, as those who have reached the most perfect state of the soul, whose mission it is to bring the rest of us along the path of learning leading to enlightenment. If that is so, then truly the lives of families of children with disabilities, and all who know them, have been enriched beyond measure. In this new millennium, may the wisdom they bring spread and grow vivid with color, like tulips in Holland. Δ

—Jan Spiegle Stinger is a Program Officer with DPHHS. At present, she is busy enjoying the tulips with her daughter, Sara.

# Women With Disabilities: *Employment, Income and Health*

**W**omen with disabilities face particularly substantial barriers to independent living. They're often poorer, in worse health, less educated and more dependent on government social service programs. Women living in rural areas face limited access to employment and economic opportunities, limited transportation options, scarce or unaffordable housing, and lack of access to health care providers who are knowledgeable about disabilities (Seekins et al., 1998). Women with disabilities face a wide range of obstacles to independent living, including limited employment opportunities, poverty, barriers to health care as well as limitations due to secondary conditions, and abuse. This may be exacerbated in rural areas due to lower levels of education, limited opportunities, and isolation.

People with disabilities are more likely to be unemployed than people without disabilities. For

all people with disabilities, living in a rural area significantly increases the probability of unemployment. Rural women with disabilities are approximately three times less likely to be employed (27%) than rural women without disabilities. In comparison, rural men with disabilities are approximately two times less likely to be employed (38%) than men without disabilities. Clearly, rural women with disabilities are the least likely to be employed of these groups.

Unemployment is synonymous with poverty, and not surprisingly, poverty is severe for women with disabilities. People with disabilities, both urban and rural, frequently have incomes at or below 100% of the 1995 federal poverty level of \$7,740 (Federal Register, 1996). Rural women with disabilities, however, are the "poorest of the poor"—80.51% make less than \$10,000 a year.

## **Safety Issues**

Women with and without disabilities face an equally high prevalence of abuse and violence, but women with physical disabilities experience abuse of longer duration and have fewer options than urban women. Leaving an abusive situation is especially problematic due to limited transportation; few (if any) rural women's

shelters; and significantly less education. (Nosek et al., 1997)

## **Health Issues:**

Women with disabilities also face challenging barriers to health care. Montana women with disabilities have described limited access to these important health care services:

1. Obstetrical care providers with knowledge about specific disabilities;
2. Screening procedures with accessible mammography and pelvic exam equipment; and
3. Adequate fertility control services and health information, especially regarding sexuality. (Szalda-Petree, Unpublished focus group testimony, 1995).

Prevention is important to women with disabilities, since significantly more women with disabilities report urinary tract infections, depression, osteoporosis, restrictive lung disease, in-

flammatory bowel disease, heart disease, seizure disorders, and kidney disease than able-bodied women (Nosek et al., 1997). Most of these secondary conditions are at least partially preventable.

University of Montana researchers found that men and women with mobility impairments experience an average of 14 secondary conditions per year. The ten most common secondary conditions experienced by women in our sample include: mobility problems; fatigue; joint/muscle pain; poor physical conditioning; chronic pain; access problems; arthritis; sleep problems; contractures; and depression. Δ

*For more information, contact:*

*Living Well with a Disability Program  
RTC on Rural Rehabilitation Services  
Rural Institute on Disabilities  
The University of Montana  
32 Campus Dr., #7056  
Missoula, MT 59812-7056  
(800) 932-4647  
(406) 243-4860 (406) 243-2349 fax  
[szalda1@selway.umt.edu](mailto:szalda1@selway.umt.edu)*

## **Resource:**

**Rural Institute: June 1999** [http://ruralinstitute.umt.edu/rtrural/general\\_disability/women\\_with\\_disabilities.htm](http://ruralinstitute.umt.edu/rtrural/general_disability/women_with_disabilities.htm)

## **Resources for Women with Disabilities**

*Center for Research on Women with Disabilities*

*Dept. of Physical Medicine & Rehabilitation*

*Baylor College of Medicine  
3440 Richmond Ave., Ste B  
Houston, TX 77046*

*Phone: 713-960-0505*

*Fax: 713-961-3555*

*[crowd@bcm.tmc.edu](mailto:crowd@bcm.tmc.edu)*

*Breast Health Access for Women with Disabilities*

*2001 Dwight Way  
Berkeley, CA 94704*

*Phone: 510-204-4866*

# Dual Diagnosis

By Marsha Armstrong, Planner/Consumer Relations Specialist  
Addictive and Mental Disorders Division, DPHHS

## Substance Abuse in Schizophrenia

*Approximately half of the patients who suffer from schizophrenia are also substance abusers at some time during the illness. The motivational drive toward abusive consumption is compounded in individuals with schizophrenia who turn toward substances with reinforcing properties to alleviate aspects of psychosis. Substance abuse persists despite and in spite of treatment with typical antipsychotics. The efficacy of newer generation antipsychotics in the reduction of substance abuse among the schizophrenic population has yet to be established, but clozapine has been shown to reduce alcohol, smoking and cocaine use.*

**Source:** Research Briefs: The National Clearinghouse for Alcohol and Drug Information—A service of SAMSHA (<http://www.health.org/res-brf/34.htm>)

Source cited by brief "Substance Abuse in Schizophrenia: A Review," Journal of Clinical Psychiatry. Source Id: 59(suppl3):26-30, 1999.

**"D**ual diagnosis" refers to an individual who has both a substance abuse or dependency problem and a coexisting psychiatric disorder. Individuals with dual diagnoses pose many challenges to providers. Several factors contribute to this. To begin with, these disorders interact in a way that compounds the person's distress and disability. People with either *one* of these disorders characteristically exhibit a form of denial that makes them resistant to treatment. Additionally, dual diagnosis makes "traditional" treatment difficult, due to the fact that both disorders have a high potential for relapse.

Epidemiological studies suggest prevalence rates of substance abuse or dependency in the general population at around 9%. However, a history of major depression or anxiety disorder appears to *double* the risk for substance abuse or dependency. Among the young, severe mentally ill population, chemical abuse rates approach or exceed 50%. Other data suggests a 20% alcohol abuse rate for persons with bipolar disorder and 70% rate for persons with an antisocial personality disorder.

There are several possible relationships between alcohol and drug use (AOD) and psychiatric symptoms or disorders, as described in the following classification model (Lehman et al., 1989; Meyer, 1986).

- AOD use can cause psychiatric symptoms and mimic psychiatric disorders.
- Acute and chronic AOD use can prompt development, provoke reemergence, or worsen the severity of psychiatric disorders.
- AOD use can mask psychiatric symptoms and disorders. Individuals may use alcohol and/or drugs, to purposely dampen unwanted psychiatric symptoms and/or to ameliorate the unwanted side effects of medications. This may inadvertently hide or change the character of psychiatric symptoms and disorders.
- AOD withdrawal can cause psychiatric symptoms and mimic psychiatric syndromes.
- Psychiatric and AOD disorders can co-exist. One disorder may prompt the emergence of the other, or the two disorders may exist independently.

Psychiatric behaviors can also mimic behaviors associated with AOD problems. The symptoms of a coexisting psychiatric disorder might be misinterpreted as poor or incomplete recovery from addiction. Psychiatric disorders may also interfere with patients' ability and motivation to participate in treatment.

Three different treatment approaches are available:

- Sequential treatment, in which the client participates in one system, then the other;
- Parallel treatment, during which the client participates in two systems simultaneously; and
- Integrated treatment, during which the client participates in a single unified and comprehensive treatment program for dual disorders.

These approaches rise from different philosophies about the nature of dual disorders, as well as differing opinions regarding the best way to treat this population. These approaches also reflect resources available in communities. Regardless of the treatment approach used, any successful treatment must include treatment engagement, treatment continuity and comprehensiveness, treatment phases, and continual reassessment and rediagnosis.

Clearly, dual disorder is a complex issue. This article has only scratched the surface, but stay tuned: the Addictive and Mental Disorders Division is in the process of including the development of dual disorders program in the legislative packet for the next session. Δ

## Bibliography:

- Dual Diagnosis Counseling the Mentally Ill Substance Abuser; Katie Evans and J. Michael Sullivan. Guilford Press. Paperback edition: March 1999. 191 pages.
- Assessment and Treatment of Patients with Coexisting Mental Illness and Alcohol and other Drug Abuse; TIP 9; CSAT. (<http://www.health.org/survey/tip.htm>)
- An Integrated Treatment Approach for Severely Mentally Ill Individuals with Substance Disorders; Kathleen Sciacca; (Printed in Chapter 6 of New Directions For Mental Health Services, No. 50, Summer 1991: Jossey-Bass, Publishers.) Available at: <http://users.erols.com/ksciacca/>

# Traumatic Brain Injury

**T**raumatic Brain Injury (TBI) is an acquired injury to the brain caused by an external physical force, which results in total or partial functional disability and/or psychosocial impairment, and which adversely affects educational performance. The term applies to open and closed head injuries resulting in impairments in one or more areas including: cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. TBI does *not* apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

## Incidence

More than one million children sustain head injuries annually; approximately 165,000 require hospitalization, though many who sustain mild brain injuries may never see a health care professional at the time of the accident. The most frequent causes are related to motor vehicle crashes, falls, sports, and abuse/assault.

## Characteristics

The Brain Injury Association calls TBI “the silent epidemic,” because many children have no visible impairments after a head injury. Symptoms can vary greatly depending upon the extent and location of the brain injury. However, impairments in one or more areas (such as cognitive functioning, physical abilities, communication, or social/behavioral functioning) are common. These impairments may be either temporary or permanent and may cause partial or total functional disability as well as psychosocial maladjustment.

Children who sustain TBI may experience a complex array of problems, including:

- Physical impairments—speech, vision, hearing and other sensory impairment, headaches, lack of fine motor coordination, spasticity of muscles, paresis or paralysis of one or both sides and seizure disorders, balance, and other gait impairments.
- Cognitive impairments—short- and long-term memory deficits, impaired concentration, slowness of thinking, and limited attention span, as well as impairments of per-

ception, communication, reading and writing skills, planning, sequencing, and judgment.

- Psychosocial-behavioral-emotional impairments—fatigue, mood swings, denial, self-centeredness, anxiety, depression, lowered self-esteem, sexual dysfunction, restlessness, lack of motivation, inability to self-monitor, difficulty with emotional control, inability to cope, agitation, excessive laughing or crying, and difficulty relating to others.

Any or all of the above impairments can occur to varying degrees. The nature of the injury and its attendant problems can range

from mild to severe. The course of recovery is very difficult to predict for any given individual. It is important to note, how-

ever, that with early and ongoing therapeutic intervention, the severity of these symptoms can decrease.

## Educational Implications

Despite its high incidence, many medical and education professionals are unaware of the consequences of childhood head injury. Students with TBI are too often inappropriately classified as having learning disabilities, emotional disturbance, or mental retardation.

*Continued on Page 8*

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*TBI is the leading cause of death and disability in children and adolescents in the United States.*

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## TBI Resources

Montana Brain Injury Association  
(406)243-5913  
Brain Injury Association  
(formerly the National Head Injury Foundation)  
1776 Massachusetts Avenue, NW  
Suite 1000  
Washington, DC 20036  
800-444-6443 (Family Helpline)  
202-296-6443  
Web Address: <http://www.biausa.org>

THINK FIRST Foundation  
22 South Washington Street  
Park Ridge, IL 60068  
708/692-2740

### Interagency Coordinating Council for State Prevention Programs (ICC)

P.O. Box 4210  
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Flathead Care

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**Rick Day**  
Director  
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**Joe Mazurek**  
Attorney General  
Department of Justice

Coordinator  
Office of Indian Affairs

## **Substance Exposed**

### **Newborns**

*During pregnancy, the use of drugs such as cocaine has been related to many different types of medical complications, including premature birth and poor growth. The long-term impact of drug use during pregnancy on the child's outcome is unclear. Some infants exposed to drugs during pregnancy may display characteristics that make caring for them quite challenging, such as irritability, lack of eye contact (gaze aversion) and difficult in regulating their behavior. Though some of these children are easily over-stimulated by the slightest noise, others require high levels of stimulation to become excited.*

*It is important to note that many of these infants are very typical in their development. There may be some long-term impact on the child's ability to learn and on their development. In early childhood they may have*

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## **Traumatic Brain Injury**

**Continued from page 7**

As a result, necessary educational and related services may not be provided within the special education program. The designation of TBI as a separate category of disability signals that schools should provide children and youth with access to neuropsychological, speech and language, educational, and other evaluations necessary to provide the information needed for the development of an appropriate individualized educational program.

While the majority of children with TBI return to school, their educational and emotional needs are likely to be very different from what they were prior to injury. Although children with TBI may seem to function much like children born with other handicapping conditions, it is important to recognize that the sudden onset of a severe disability resulting from trauma is very different. Children with brain injuries can often remember how they were before the trauma, which can result in a constellation of emotional and psychosocial problems not usually present in children with congenital disabilities. Further, the trauma impacts family, friends, and professionals who recall what the child was like prior to injury and who have difficulty shifting and adjusting goals and expectations.

Careful planning for school re-entry (including establishing linkages between the trauma center/rehabilitation hospital and the special education team at the school) is extremely important in meeting the needs of the child. It will be important to determine whether the child needs to relearn material previously known. Supervision may be needed (i.e. between the classroom and restroom) as the child may have difficulty with orientation. Because the child's short-term memory may be impaired, what appears to have been learned may be forgotten later in the day.

To work constructively with students with TBI, educators may need to:

- Provide repetition and consistency;
- Demonstrate new tasks, state instructions, and provide examples to illustrate ideas and concepts;
- Avoid figurative language;
- Reinforce lengthening periods of attention to appropriate tasks;
- Probe skill acquisition frequently and provide repeated practice;

- Teach compensatory strategies for increasing memory;
- Be prepared for students' reduced stamina and increased fatigue and provide rest breaks as needed; and
- Keep the environment as distraction-free as possible.

Initially, it may be important for teachers to gauge whether the child can follow one-step instructions well before challenging the child with a sequence of two or more directions. Often attention is focused on the child's disabilities after the injury, which reduces self-esteem. It is therefore important to build opportunities for success and to maximize the child's strengths.

The regulations for Public Law 101-476, the Individuals with Disabilities Education Act (IDEA)—formerly the Education of the Handicapped Act—now include Traumatic Brain Injury (TBI) as a separate disability category. While children with TBI have always been eligible for special education and related services, it should be easier for them to receive services under this new category.

### **Source:**

*National Information Center for Children and Youth with Disabilities  
P.O. Box 1492  
Washington, DC 20013-1492  
1-800-695-0285 (Voice/TT)  
(202) 884-8200 (Voice/TT)*

*Kid Source Online: <http://www.kidsource.com/NICHCY/brain.html>*





# Does Having ADHD Lead to Drug Abuse?

**T**

he results of two studies are at odds over whether children with Attention Deficit Hyperactivity Disorder (ADHD) are more prone to abuse drugs as adults. The studies include a report from the University of California at Berkeley, which says that children with severe ADHD symptoms tend to smoke early and abuse stimulants as adults. The second is a study by researchers at Massachusetts General Hospital, the Harvard School of Public Health, and Harvard Medical School, which determined that children with ADHD *who receive treatment*, including stimulant medication, are less likely to abuse drugs as adults. Both studies were funded, in part, by the National Institute on Drug Abuse.

## The Berkeley Study

The Berkeley study, released last year, was conducted by Nadine Lambert, Director of the School Psychology Program at the university's College of Education. Her research is based on an ongoing 26-year study of 492 children, half of whom have varying degrees of ADHD. The other half served as a control group. Lambert found that the more severe the ADHD, the more likely later cocaine abuse and regular smoking behavior. In Lambert's study, she does not distinguish between children who have been treated with Ritalin and those who have not. Instead, she is concerned with analyzing drug usage in relation to the severity of ADHD symptoms.

Lambert suggests two explanations for the higher rate of dependence on stimulants and tobacco among individuals with severe ADHD symptoms, some of whom have been treated with stimulant medications:

### 1. Self-medicating theory:

Those suffering from severe ADHD symptoms are more likely to abuse tobacco, cocaine and other stimulants, as opposed to depressants such as alcohol or marijuana. Lambert suggests that they may use the drugs in an effort to control their ADHD symptoms. The disorder, however, may compromise their ability to control or self-regulate, leading to potential drug dependency.

### 2. Sensitization hypotheses:

Based on animal studies, the theory is that exposure to Ritalin may predispose children to the stimulating effects of cocaine, tobacco and amphetamines.

## The Harvard Study

The Harvard study compared the incidence of substance use disorders in 56 boys with ADHD who had been treated with stimulants for an average of four years, 19 boys with ADHD who had not been treated with stimulants, and 137 boys who did not have ADHD. All were evaluated for substance use disorders involving alcohol, marijuana, or cocaine. Results indicated that 75 percent of the unmedicated ADHD boys had at least one substance use disorder, as compared to 25 percent of the medicated ADHD boys and 18 percent of those without ADHD.

In previous studies, the same Harvard researchers found that almost twice as many adults with ADHD developed a least one substance use disorder in their lives, as compared to those without ADHD. They suggested that the adults with ADHD who developed the disorder in childhood were, in most cases, not diagnosed or treated until much later and therefore did not have a history of treatment with stimulant medications.

*The Harvard researchers' current theory is that if the underlying disorder is treated early, the probability that individuals with ADHD will use drugs as adults will be decreased. Δ*

### Source:

*The Special Educator*, Vol. 15, Iss. 3.

**For more information** on Lambert's research, contact the University of California at Berkeley at (510-642-3734). To read the Massachusetts study, consult the August 2, 1999 issue of the *Journal of Pediatrics*.

### Resource:

*PLUK News: October/November 1000.*  
Page 7. <http://www.pluk.org>

### Continued from page 8

*difficulty relating to the environment, making friends, playing like other children and showing strong feelings towards their mother or primary caretakers. The emotional and social development of these children appears to be more affected than intellectual development. In general, their IQ scores fall in the low normal range. The ability to initiate brief or one-step activities is present, but overall, these children do not seem to be good initiators. The basic physical characteristics among cocaine affected babies include being smaller at birth and having a slightly smaller head circumference.*

### Source:

<http://www.dbpeds.org/usf/conditions/articles/substanc.html>

*Pediatric Development and Behavior*

*Developmental Behavioral Pediatrics Online Community—dbpeds.org*

# Posttraumatic Stress Disorder

By Erin Jemison, VISTA

## Upcoming Themes

— Intergenerational Mentoring

— Nuts & Bolts:  
(The How-to Issue)

— Migration & Mobility

— Tobacco

— Poverty

If you have something to say  
about one of the upcoming  
themes, drop us a line! We'd  
love to hear from you.

Vicki & Jan

In observing children who have witnessed domestic violence, clinicians have documented many of the symptoms associated with Posttraumatic Stress Disorder (PTSD). The American Psychiatric Association classifies PTSD (or PTSS: Posttraumatic Stress Syndrome) as the new terminology for describing the "effects of war upon war survivors in this century." We now know that PTSD is also found in survivors of many other traumas, including rape, domestic violence, child abuse, natural disasters, serious accidents, and crime.

In their well-known work, *Children of Battered Women*, authors Jaffe, Wolfe and Wilson discuss PTSD and the increasing awareness of its diagnosis in children who have witnessed domestic violence. The following is an excerpt from their work.

**"The applicability of the PTSD disorder to children's exposure to family violence is straightforward. Evidence . . . suggests that many of the reactions in children can be classified as 'trauma responses,' most notably their proclivity to explosive bursts of anger and aggression, their fixation on the trauma and reduction of normal, routine activities, and somatic and emotional complaints. Because the emotional development of children is intimately connected with the safety and nurturance provided by their family environment, they suffer a loss of faith that there is order and continuity in life (Van der Kolk, 1987). Even more damaging is the concern that the family itself plays the most crucial role in protecting the child from traumatization and assisting in his or her recovery. Thus the notion of posttraumatic stress implies that children who chronically witness . . . abuse in their homes may display emotional symptomatology at some point in time that may be quite far removed from the initial traumatic events. Furthermore, such symptoms may not be readily detectable as being PTSD-related, because they may be expressed in a manner that disguises their origin . . . (consider, for example, juvenile violence, running away from home, and extreme oppositional behavior.)" (pp. 72-3)**

Even though ten percent of the population has been affected by clinically diagnosable PTSD, it has often been misunderstood or misdiagnosed. It often occurs with—or can lead to—depression (APA Online, Public Information). It has also been mistaken for Borderline Bi-Polar Disorder, and some forms of schizophrenia. ([www.lighthouse.aculink.net/domesticviolence/trauma.html](http://www.lighthouse.aculink.net/domesticviolence/trauma.html)).

Symptoms generally appear within three months of the traumatic event(s), and can range from mild to severe. According to the

American Psychiatric Association, Post Traumatic Stress Syndrome "... refers to a cluster of symptoms—including disturbed sleep and recurring nightmares—experienced by survivors of especially traumatic events." (APA Online, Public Information.) Other symptoms can include irritability, rage, flashbacks, avoidance, anxiety, insomnia, aggression, numbness, depression and/or guilt. Finally, PTSD can manifest as "hyperarousal," a state in which the victim acts as if he/she is still under threat of the original trauma.

## Treatment

Everyone who experiences trauma does not require treatment: some recover with the help of family, friends or clergy. Others need professional treatment to recover from the psychological damage resulting from experiencing, witnessing or participating in a traumatic event. Professionals have experienced good success in treating PTSD, and use a variety of methods including behavior therapy, psychotherapy, family therapy, discussion groups or peer-counseling, and medication. In general, though, treatment is cognitive rather than medicinal. (APA Online, Public Information.) Δ

## Resources:

<http://www.psych.org>  
[http://www.lighthouse.aculink.net/domestic\\_violence/trauma](http://www.lighthouse.aculink.net/domestic_violence/trauma)  
[http://www.adaa.org/4\\_info/4f/01.htm](http://www.adaa.org/4_info/4f/01.htm)  
<http://www.nimh.nih.gov/anxiety/anxiety/ptsd/ptsdinfo>

## Source:

KIDS CORNER, Volume I, Issue 1 August 1999, a newsletter published by the Montana Coalition Against Domestic and Sexual Violence

P.O. Box 633  
Helena, MT 59624  
(406) 443-7794 (phone)  
E-mail: [mcadsv@mt.net](mailto:mcadsv@mt.net)

# Hearing Loss



earing loss is a physiological, psychological, or anatomical abnormality affecting the ability to accurately receive, interpret, or process sound waves. *More than 30 million people nationwide have some degree of hearing loss.* Hearing loss affects people of all ages, and this kind of sensory deprivation changes a person's life dramatically.

## Types of Hearing Disorders

Otitis media, or inflammation of the middle ear, is the leading cause of hearing loss in children. "Otitis prone" children have two or more ear infections annually and are at high-risk for residual hearing loss. Infants and toddlers with undiagnosed auditory deficits are at risk for speech and language impediments.

Women between 20 and 40 are at risk for developing otosclerosis. This heredity condition is characterized by irregular calcification of the stapes. Tinnitus, with ringing or noises in the ears, is the primary symptom, and this may worsen during pregnancy. Undiagnosed otosclerosis leads to deafness.

Sensorineural hearing disorders impair sound-wave transmission from the inner ear through the auditory nerve. More common in men, these disorders affect the ability to hear high-pitched frequencies and to understand conversation. Even though the majority of sensorineural hearing disorders are permanent, most are *preventable*. Mumps, German

measles, head injuries, and occupational noise can all cause this form of hearing impairment.

In the United States, occupational deafness is among the 10 leading occupational diseases, with about 11 million to 12 million workers experiencing long-term exposure to noise levels in excess of 85 decibels. The Occupational Health and Safety Administration mandates industries with noise levels of 85 decibels or more to institute hearing conservation programs.

Presbycusis is progressive hearing loss due to age. Approximately 30 to 35 percent of people age 65 to 75 have hearing loss, increasing to 40 percent of those over the age of 75. Undiagnosed hearing loss in the elderly can lead to inaccurate conclusions that may hinder identification and treatment of this condition. Δ

### Source:

Nurse Week/Health Week: for the well-connected health professional

<http://www.nurseweek.com>

For more information, refer to:

1. Department of Health and Human Services. (1994). Vital and Human Statistics. U.S. Department of Health and Human Services. <http://www.hhs.gov/>
2. National Institute on Deafness and Other Communication Disorders. (1997). [Online]. Available at <http://www.nih.gov/nidcd/>

# Visual Impairment



he leading causes of blindness will double their impact in the coming years as the nation's 76 million Baby Boomers reach older adulthood. This dramatic increase in age-related eye disease threatens to overwhelm the nation's health care resources and diminish the quality of life for millions. In fact, by the year 2030, twice as many people will be blind as are today. Macular degeneration will continue to be the leading cause of blindness, and there will be a near doubling of the total cases of glaucoma.

1. Vision impairment affects a significant proportion of middle-aged and older Americans. One in six adults (17%), age

45 and older, representing 13.5 million Americans, report some form of vision impairment.

2. The proportion of adults reporting some form of visual impairment increases dramatically with age.
  - 15% of adults age 45-64 years, representing 7.2 million persons and 17% of adults age 65-74 years, representing 3.1 million people, report impairment.
  - 26% of adults age 75 years and older, *one in four*, representing 3.5 million people, report impairment.

### Montana Resources:

Montana Brain Injury Assn.  
(406)243-5913

Montana Association  
for the Blind  
(406)453-0452

Contact: Kay Kjellstrom

Montana Deaf and Hard of  
Hearing Services  
(406)771-9053

Montana Association  
for the Deaf  
(406)761-0769tty

Developmental Disabilities  
Program  
(406)444-2591

Vocational Rehabilitation  
Program  
(406)444-2590

Montana Advocacy Program  
(800)245-4743

Addictive and Mental  
Disorders Division  
(406)444-3964

Developmental Disabilities  
Planning and Advisory Council  
(406)444-1334

Continued on Page 12

## Glossary

### **Visual Impairment:** Blindness

in one or both eyes, or any other trouble seeing even when wearing glasses.

### **Severe Visual Impairment:**

The inability to see to read ordinary newspaper print even when wearing glasses (includes blindness in both eyes).

### **Legally Blind:** Clinically

measured visual acuity of 20/200 or less, or a visual field in the better eye after optimal correction of 20 degrees or less.

### **Montana Resource:**

Montana Association  
for the Blind

Contact: Kay Kjellstrom:  
(406)453-0452

## Visual Impairment

*Continued from page 11*

3. Although self-reported vision impairment cuts across all social and economic strata, specific groups of Americans are at greater risk. In general, vision impairment is more prevalent among those who have fewer social and economic resources.

— Persons with vision impairments, compared to the non-impaired, are more likely to be: women (62% vs. 53%); poor; that is, with incomes no higher than 150% of the poverty level (35% vs. 19%); unmarried (46% vs. 36%); living alone (34% vs. 27%); non-white (23% vs. 17%); not a high school graduate (41% vs. 19%); in fair or poor general health (45% vs. 24%); and lack health insurance (17% vs. 13%).

4. Similarly, issues of gender, poverty, marital status, living arrangements, ethnicity, education, and health distinguish people with severe vision impairments from those with moderate vision impairments.

— Persons with severe vision impairments, compared to those with moderate impairments, are more likely to be: women (66% vs. 58%); poor (39% vs. 30%); unmarried (49% vs. 42%); living alone (37% vs. 31%); non-white (29% vs. 16%); not a high school

graduate (44% vs. 37%); in fair or poor health (50% vs. 39%); and lack health insurance (25% vs. 8%).

### **Resource:**

*Lighthouse International: A Study by the Arlene R. Gordon Research Institute by Louis Harris and Associates, Inc. Fieldwork: April, 1994. Full text available at: <http://www.lighthouse.org>*

## Childhood Blindness

An estimated 1.4 million children (aged 14 and younger) in the world are classified as blind, defined as a corrected visual acuity in the better eye of less than 3/60 (count fingers at 3m) or a corresponding visual field loss in the better eye with best possible correction.

Vitamin A deficiency is the leading worldwide cause of childhood blindness and is the reason behind 70% of the 500,000 annual cases of childhood blindness. Among children under 5 years of age, prenatal cataract is the leading cause of legal blindness, accounting for 16% of all cases.

Statistics on Children and Visual Impairment: Lighthouse International.  
[http://www.lighthouse.org/about\\_main.htm](http://www.lighthouse.org/about_main.htm)

Lighthouse International is a leading worldwide resource on vision impairment and vision rehabilitation.

## EVENTS CALENDAR

July 2000

**MYLF: 1<sup>st</sup> Annual Montana Youth Leadership Forum for Students with Disabilities**

July 24-28, 2000

Montana State University, Billings

Contact: 1-888-866-3822, Extension 2095 or  
1-406-657-2095

**Montana Early Childhood Future Search Conference**

**Creating a Vision for Our Young Children and Families**

April 12-14, 2000

Grouse Mountain Lodge—Whitefish, Montana

Contact: Mary Jane Standaert—406-444-0589

**Montana Youth 2000A Celebration of Prevention in Montana**

April 2-4

Butte, Montana Ramada Copper King Inn

For more information, contact Dan Haffey, Butte Silver Bow Chemical Dependency Center, 406-723-4001 or see the insert in this issue of *The Prevention Connection*

# ***Lifespan Respite: Respectful Support for Montana Families***

*Submitted by Sarah Lipscomb, Montana Council for Families*

***"Respite care" is defined as temporary relief for caregivers and families caring for children and adults with special needs or concerns. "Lifespan" is an information and referral agency connecting families with trained respite care providers who can give them a break from the extraordinary demands of providing ongoing care for their loved ones.***

**L**ifespan provides a point of contact for families and individuals needing respite care services. A Lifespan Respite System combines the tasks of recruitment, training, and referral for all families, regardless of their developmental stage or the particular challenge or problem evoking their need for community support. Collaboration makes better use of existing resources and provides the focus and staffing needed to generate additional financial support and volunteer services.

## ***Lifespan Respite Supports Montana Families***

### ***Prevention:***

Respite care reduces family and caregiver stress, enhances family and caregiver coping ability and strengthens family ability to meet the challenging demands of caring for individuals with special needs.

Lifespan Respite Programs assist families outside the system who are identified as having a critical need for relief, as well as those who qualify for state paid respite care.

### ***Cost Effectiveness:***

Supporting the efforts of families and caregivers so that they can care for individuals with special needs at home is efficient, cost effective and humane. Coordinated, non-categorical respite care makes better use of existing respite resources.

### ***Self Sufficiency:***

Families receiving occasional respite care relief are less likely to request admission of an individual with special needs to nursing homes, foster care or other out-of-home care at public expense.

### ***Safety:***

Respite care reduces the risk of abuse and neglect of children, senior citizens, and other vulnerable groups.

### ***Community Service:***

Lifespan respite provides the focus and staffing to generate additional community financial and volunteer support for families.

### ***Measurable Results:***

Lifespan projects will be capable of demonstrating more efficient use of existing resources, expanded community respite resources, and increased use of respite care services.

### ***Community and Customer Focus:***

Lifespan Respite overcomes categorical funding to provide a single point of contact for families.

### ***Service Integration:***

Lifespan Respite integrates existing respite programs within the Department of Health and Human Services and merges them with private sector community efforts to support families.

### ***Program News***

This September, at the Montana Crisis Care and Respite Conference, thirty representatives of community respite programs and consumers met to plan for Lifespan Respite in Montana. The heart of this year's conference focused on an innovative approach to delivery of respite services piloted in Miles City and Billings. Lifespan Respite Care brings together interested parties from across the categorical fields of child abuse prevention, developmental disabilities, aging, mental health, juvenile justice, and similar programs to examine commonalities among their various respite programs. These programs recognize that providing occasional relief makes it less likely such families will be overwhelmed by the demands of care giving and request admission of family members to nursing homes, foster care or other high cost residential care. Δ



## ***American Indians and Disability***

Today, of 1.9 million American Indians and Alaskan Natives, an estimated 26% (more than 490,000 people affiliated with over 554 federally-recognized tribes) live with a significant disability including approximately 94 thousand who have a mobility or self-care limitation. The majority live on or near reservations in remote, rural areas. Many of these people, like their counterparts in general society, need or will need support services to continue living in their homes and participating in tribal life.

### ***Source:***

[http://ruralinstitute.umn.edu/rtrcrural/Indian/american\\_indian\\_common\\_threads.htm](http://ruralinstitute.umn.edu/rtrcrural/Indian/american_indian_common_threads.htm)



## Montana Centers for Independent Living

The Montana Centers for Independent Living offer non-residential services for people with disabilities. Although these centers provide services to anyone with a disability regardless of age, many youth with disabilities can benefit from these services as they make the transition from school to adult life. Learning to manage independently while living with a disability is critical to overall success in achieving the level of independence desired.

The Montana Centers for Independent Living can help youth with disabilities understand disability culture and disability pride. The centers are private nonprofit corporations, run primarily by people with disabilities.

*Continued on page 15*

# Program Provider Spotlight

*Adult Foster Care Program, Golden Triangle Community Mental Health Center*

**T**he Adult Foster Care program in Helena is serving 24 adults with seriously disabling mental illness (SDMI). Golden Triangle is currently implementing the program in the Great Falls area as well. The program provides a supportive living environment for adults with serious mental illness who have had difficulty living independently in the community due to underdeveloped skills, and/or difficulty managing symptoms of their illness. Adult Foster Care offers these individuals a better quality of life in the community, and supports their successful transition to independent community living. Adult Foster Care has proven to be a successful, less restrictive, and lower-cost alternative to hospitalization.

The success of Adult Foster Care comes from its intensive team approach to meeting the specific needs of the individual. Consumers are provided a choice of licensed Adult

Foster Care providers. The foster care provider is able to offer consumers a welcoming, supportive "family" environment and essential structure to support daily living. Consumers are also able to access a wide array of other essential and appropriate services to meet their individual needs. The treatment team includes the adult foster care specialist, the adult foster care provider, family members, therapist, psychiatrist, nurse, community support specialist, CD counselor, adult education, day treatment, and supportive employment. Δ

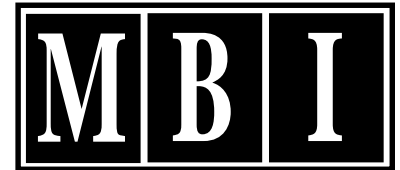
*For more information on Adult Foster Care or assistance in developing this program in your community, contact Jeff Sturm or Michelle Money at 443-7151.*

### Resource:

This article came from Montana Department of Public Health and Human Services Bulletin, published on-line at [www.dphhs.state.mt.us](http://www.dphhs.state.mt.us) under the "Hot Issues" section.

## MBI In Action

*By Susan Dotter, Helena Middle School Counselor*



**H**elena Middle School has participated in the Montana Behavior Initiative (MBI) for the past three years. Clear expectations for student behaviors have been developed, with a goal of improved behavior in the hallways.

In our focus on behavior and expectations, it came to the attention of the MBI Team that students with disabilities experience their own unique difficulties in the hallways. As a result, these students were asked to develop a plan to help make other HMS students aware of the problems encountered by students with disabilities.

Clinton is a 7<sup>th</sup> grade student who uses a wheelchair. With the help of the district's occupational therapist and a few of his classmates, Clinton made a short video to explain his disability and to ask for cooperation from other students when they encountered his wheelchair in the crowded hallways. Copies of the video were distributed by the MBI Team

and shown to all students during advisor period. When asked if he thought that the video had helped his situation, and how things were currently going in the hallway, Clinton summed it up with, "Excellent!"

Kayla, another 7<sup>th</sup> grader, is a blind student, new to HMS this year. One of Kayla's goals was to be able to travel the hallways from class to class without assistance from a special education paraprofessional. Kayla chose to speak to the student body over the intercom. She told everyone about her disability and her goal. She asked all students

to offer support in the hallways by following the directions and staying to the right, and by treating her and one another with respect.

Kayla reports, "It's easy to get around in the

hallway. Kids get out of my way...most of the time. If they don't, they either trip over my cane or someone else will tell them to get out of the way. I go to all my classes by myself now — with my friends." Δ

***As a result of Helena Middle School's MBI activities, the number of hallway referrals has decreased by approximately 45% since the 1996-97 school year.***

# The Shared Vision Project

By Deborah Wetsit, Ph.D., Project Director  
Shared Vision Project: Circles of Care  
In-Care Network, Inc., Billings

**T**he Shared Vision Project has been charged with planning, designing and assessing the feasibility of implementing a culturally-appropriate mental health service delivery model for American Indian/Alaskan Native children dealing with serious emotional disturbances and their families. The project is working with members of all seven American Indian reservations and one urban American Indian community.

The first year of the project was devoted to strategic planning, which included collecting baseline data for use in developing:

- A statewide profile of the current use of the mental health system by American Indian children with serious emotional disturbances and their families.
- Tribal profiles; and
- The definition of culturally-appropriate standards.

The Shared Vision Project has now started its second year and continues to build momentum. Some of the highlights include:

## Quantitative Data Collection

The Project is working with the Indian Health Service and the State of Montana to determine the numbers of American Indian children receiving mental health services. Gathering this data will permit the development of a baseline profile (i.e., how many children are receiving mental health services and the nature of these services). At this point, the data has been collected and is now in the analysis stage.

## Qualitative Data Collection

The Project also collected information from focus groups, First Talker Society meetings (cross-section representation from each community), and telephone surveys of foster parents. Focus groups were convened on nearly all seven Indian reservations and in the Billings community. Local Site Coordinators were essential to the success of these group meetings.

As the information collected is analyzed, it, too, will be shared through additional focus groups and First Talker Society meetings. These meetings are anticipated to begin again in February or March. A foster parent survey was developed and conducted to determine which cul-

turally based intervention strategies are used in this environment, and to determine what foster parents find to be effective in working with American Indian children. The results of these efforts are also in the analysis stage.

All data analysis will be reviewed by tribal officials, Tribal Health CEOs, State, and Indian Health representatives before findings are released to the public.

## Advisory Committee

An advisory committee representing all seven Montana Indian reservations, the urban Indian community, and service providers was established during the first project year. This committee held its second meeting in December to review the status of the Shared Vision Project and to advise the staff in the successful attainment of the Project's goals. Representation was excellent, and included individuals from Tribal Councils, Tribal Health Agencies, the Indian Health Service, the State of Montana, as well as tribal elders, social workers, school administrators, tribal judicial representatives, and other community members.

## Staff

Project staff includes: Bill Snell, Jr., Executive Director, Joe Browning, Linda Parker, Deborah Wetsit, Tony Herrera and Reno Charette. All have backgrounds in direct service delivery to American Indian children and tribal communities, as well as in research and administration. Ms. Karla Two Two recently joined the Project as the receptionist. She is a welcome addition to the team. Δ



**Continued from page 14**

The array of services provided include:

- Information and referral;
- Outreach;
- Training in independent living skills;
- Peer mentoring;
- Individual and systems advocacy;
- Americans With Disabilities Act barrier removal technical assistance;
- Rehabilitation technology;
- Technical assistance; and
- Self-directed personal assistance services.

The centers provide statewide coverage through outreach workers and can be reached at the following locations:

- Living Independently for Today and Tomorrow
  - Billings, Miles City and Glendive: 800-669-6319
- Montana Independent Living Project
  - Helena: 800-735-6457
- North Central Independent Living Services
  - Great Falls and Glasgow: 800-823-6245
- Summit Independent Living Center
  - Missoula, Kalispell, Ronan and Hamilton: 800-398-9002

# Tribal Probation Officer Alcohol-Related Birth Defects Training Project

By June Hermanson

## **The Montana Center on Disabilities**

*The Montana Center on Disabilities, a Montana State University-Billings affiliate, is dedicated to promoting the inclusion of people with disabilities of all ages and cultural backgrounds into their communities.*

*A key distinguishing feature of the Montana Center is that all its programs are model demonstration programs that have research and training components as well as numerous university and community partners.*

*The Montana Center is committed to continual evaluation of the needs of individuals with disabilities and their families and to the use of state-of-the-art technology to achieve this mission.*

### **For more information contact:**

*www.msubillings.edu/mtcd  
Special Education Bldg.  
1500 North 30th Street  
Billings, MT 59101  
(406) 657-2312 (voice/tdd)  
1-888-866-3822  
(406) 657-2313 (fax)*

**I**n 1990, the National Institute on Alcohol Abuse and Alcoholism estimated that out of 1,000 children, 1.9 are born with Fetal Alcohol Effect (FAE). This rate is nearly double the rate of Down's Syndrome, and three times greater than those born with FAS. Current research shows that an array of secondary disabilities are associated with FAS/E and become more apparent as the child matures, with primary manifestation occurring after the age of twelve. In general, this study suggests that it would not be unreasonable to expect that approximately 40% of the youth affected with FAS/E will be involved with the youth probation system.

The Montana Center on Disabilities was recently awarded a grant by the State Board of Crime Control to train the tribal juvenile probation officers serving Montana's seven Indian reservations. Representatives attending the training were prepared to return to their respective reservations and train local groups of service providers on dealing with youth affected by FAS/E who are also involved with juvenile probation systems.

Utilizing the information from current re-

search, as well as past and present probation officer training, the Montana Center on Disabilities will develop a manual that will provide project data on the progress and outcomes of implementing these strategies in field situations. This manual will be disseminated to all juvenile probation offices in Montana. There will also be a limited number of copies available for others interested in this material.

The Montana Center on Disabilities continues in its efforts to stay on the cutting edge of new information about FAS/E. In November, two staff members from the Montana Center, June Hermanson and Tina Haogland, attended Seattle-based conference, *Meeting the Needs of Individuals with FAS/E*. Information was shared with regard to the efforts of the Interagency Coordination Committee on Fetal Alcohol Syndrome taking place on a national level. The Interagency Coordination Committee has been developed to promote research, improve diagnosis, educate communities, and improve correctional interventions for children with FAS/E. This collaboration represents an encouraging step forward. Δ

*For more information, or to request a copy of the manual, please contact June Hermanson, Janet Nyberg, or Tina Haogland at the Montana Center on Disabilities at 1-888-866-3822.*

The effects of alcohol abuse among pregnant women are extremely serious. Children affected by Fetal Alcohol Syndrome (FAS) present several physical and behavioral symptoms. FAS is one of the most common causes of mental retardation and behavior disorders. The distinctive physical features include a small head, low but prominent ears, droopy eyelids, increased distance between the upper lip and nose, poorly developed cheekbones and a thin upper lip. Children with Fetal Alcohol Syndrome may have seizures and/or abnormalities of bones and joints. Neurological abnormalities and growth problems are also major physical characteristics of this syndrome. Behavioral characteristics of FAS can include hyperactivity and inability to or difficulty in understanding cause and effect relationships. As a result of cognitive and behavioral limitations, these children often require specialized education strategies.

FAS differs from the less severe condition of Fetal Alcohol Effect (FAE). Children

with FAS have symptoms in three categories; facial abnormalities, growth problems and neurological abnormalities. FAE is the category reserved for children evidencing symptoms in two of the three categories.

- In the general public, an alcoholic woman has a 10% chance of giving birth to a child with FAS.
- 30-40% of alcoholic women may give birth to a child with FAE.
- Approximately 1-2 children per 1,000 will have FAS.
- FAE is estimated to affect 5-10 children per 1,000 births, or 0.5 per cent, although this rate is significantly higher in some social and ethnic groups as a result of higher rates of alcohol abuse.

### **Resource**

Pediatric Development and Behavior  
Developmental Behavioral Pediatrics Online  
Community dbpeds.org  
<http://www.dbpeds.org/usf/conditions/articles/fas.html>



# Montana Birth Outcome Monitoring System

By Jan Baker, Special Health Services

**M**ontana reports approximately 11,000 births per year. Of these, roughly 2% have a birth defect recorded on the birth certificate. Through Title V Maternal Child Health (MCH) sponsored outreach clinics, nearly all children with cleft/craniofacial anomalies, the majority of which are visible at birth, are identified and offered services through regional clinics. For the small number of newborns who have neural tube defects, however, there is no mechanism in place for tracking with an eye to optimizing services and preventing recurrences.

With CDC funding, we have developed a Montana Birth Outcome Monitoring System to accomplish three goals:

1. Ensure timely identification and surveillance of newborns and infants with targeted birth outcomes, including cleft lip/palate, neural tube defects, congenital heart disease, and congenital hypothyroidism.
2. Decrease the incidence of these birth defects through population and client specific education.
3. Improve services to affected newborns in order to promote healthy outcomes for infants and families.

This program will connect many community services and providers, including physicians and hospitals. Local public health departments

providing home visiting to pregnant women and special needs children will be included, along with Part C of Individuals with Disabilities Act (IDEA) providers, and the Montana Medical Genetics Program, which has long been affiliated with the Department of Public Health and Human Services. Together, these programs assist families whose children have special health care needs.

The Title V Children with Special Health Care Needs Program, Special Health Services, has been responsible for collecting data relative to Montana children with special health care needs. This year a component will be added to track birth defects using a link with birth outcomes through the Vital Records Bureau. The purpose of this link is to ensure timely intervention including prevention education for children and families. Δ

*For additional information, contact Jan Baker, Special Health Services, at 444-6858 or :*

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The opinions expressed herein are not necessarily those of The Prevention Resource Center and the Addictive and Mental Disorders Division of the Montana Department of Public Health and Human Services.

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## Parents Let's Unite for Kids (PLUK)

**W**ho are we?

- We are members of a statewide group that supports families in their desire to help people with disabilities lead productive lives.
- We are people with disabilities, parents, professionals, relatives, and friends who want to insure that persons with disabilities participate in the community and have access to high quality educational, medical and rehabilitation services.
- PLUK is a private, nonprofit organization formed in 1984 by parents of children with disabilities and chronic illnesses.

### What do we do?

- PLUK was formed to provide information, support, training and assistance so that parents could aid their children at home, at school and as adults. PLUK is an organization of parents and other caring individuals who serve families and individuals with disabilities of any age and at no cost.

### How and why did PLUK get started?

- PLUK's founders felt strongly that parents of children with disabilities need to band together to give each other information and support. It seemed foolish for each new parent to try to learn all over again what

other parents already knew and were willingly to share. It also seemed important for parents to lend one another support because healing takes place when people who share a common problem work together to find solutions. Δ

Contact us at  
[www.pluk.org](http://www.pluk.org) or  
516 N 32<sup>nd</sup> Street  
Billings, MT 59101  
(800)222-7585.

# The Way We Really Are: Coming to Terms With America's Changing Families

Stephanie Coontz (New York: Basic Books, 1997). 238 pp. \$15.00

## Childhood Hearing Loss

— Otitis media is inflammation in the middle ear usually associated with fluid build-up. It occurs most frequently in children, ranking second to the common cold as the most common health problem in preschool children.

— When otitis media occurs over and over again, permanent hearing loss can result.

— Children learn speech and language from listening to other people talk and the first few years of life are especially critical developmentally. If hearing loss exists, critical delays in speech and language development may occur.

— Otitis media without infection presents a special problem because symptoms of pain and fever are usually not present. Therefore, weeks, and even months, can go by before parents suspect a problem. During this time, the child could miss out on hearing the speech and language needed for normal development.

**Those who cannot recall history are condemned to repeat it.**

—George Santayana

**S**tephanie Coontz, a professor at Evergreen State University in Olympia, Washington and author of an earlier book, *The Way We Never Were*, might be called an iconoclast for the way she takes common myths about American families and dismantles them. Coontz takes the position that there never was a golden age of family life, “a time when all families were capable of meeting the needs of their members and protecting them from poverty, violence, or sexual exploitation.”

**“When families succeeded, it was often for reasons quite different than stereotypes about the past suggest,” Coontz observes, “We cannot help contemporary families if we accept a one-dimensional analysis of where their problems originate, insist there is only one blueprint for how all families should look and act.”**

There are no easy answers and surefire techniques for raising kids. Never have been. Never will be. The fact is that there is no single political formula or “good values” patent medicine, no prescription that can guarantee a healthy marriage, an effective parent, or a “normal” child. The problems facing inner-city families who don’t have access to jobs, parks, libraries or safe streets are very different from those facing working parents saddled with overtime, or who can’t take parental leave to care for sick children. The solutions have to be different, too.

The overriding theme of *The Way We Really Are* is that we must get beyond a sound bite mentality and nostalgia for a 1950’s utopia that never really existed. Instead, we’ve got to get to work with the families we have, rather than waste time mourning those we wish we had.

Some of Coontz’s key observations include:

— Young people do better on almost every level when they have meaningful in-



volvement in useful and necessary tasks.

- The failure to address the roots of gender differences perpetuates the problem of communication between the sexes.
- What we call the crisis of youth may in fact be a crisis of class and poverty.
- Most public space has become “adultified.” Kids are allowed only if they’re young enough to be in the care of parents. “But where,” Coontz asks, “in your town are teenagers welcome on their own?”
- School schedules do not match parents’ work schedules. Research by the Office of Juvenile Justice and others indicates that children are more likely to get into trouble between 3 and 6 p.m. than after midnight.
- Pundits who bombard us with “factoids” about such topics as divorce do us a disservice. People don’t understand that statisticians use staying married for 40 years as the measure of marital success when they state that “one in two or three marriages will end in divorce.” While the number of people who divorce is certainly unprecedented, so is the number of couples who live to celebrate 40<sup>th</sup> wedding anniversaries.

It’s time, Coontz says, to have a serious discussion about how to build the support systems that modern families need. And what parents need is more concrete research about how different families can create processes that work given the dynamics of individual families. This would be much more useful than trying to apply political rhetoric to the problems of daily life.

The first step, she says, is to get rid of what doesn’t work: fragmentation of services; red tape; denial of flexibility to front line workers; destroying successful programs by asking caseworkers to take on new problems and bigger case loads; failing to hire people who can help families cope with daily challenges; or, conversely,

# Dear Professor Prevention . . .

*What is meant, exactly, when people use the term "developmental disabilities?"*

Signed,  
Thirsting for Knowledge

Dear Thirsting:

"Developmental disabilities" is a term used by many states and school districts in the United States; this global term covers many specific disorders. Developmental disabilities are generally more severe, chronic, and medically oriented than disabilities covered by other terms. Examples of developmental disabilities would include autism, cerebral palsy, epilepsy, mental retardation, severe emotionally handicapped and certain sensory and severe language disorders. The severity of these conditions, singularly or in combination, makes it likely that the individual will require indefinite assistance in major life activities. (Source: Pediatric Development and Behavior, Developmental Behavioral Pediatrics Online Community.)

Here in Montana, the definition is slightly different. As legislatively defined in Section 53-20202 of the Montana Codes Annotated (MCA), "Developmental Disabilities means disabilities attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurological handicapping condition that is closely related to mental retardation and requiring treatment similar to that required by mentally retarded individuals if the disability originated before the person attained age 18, has continued or

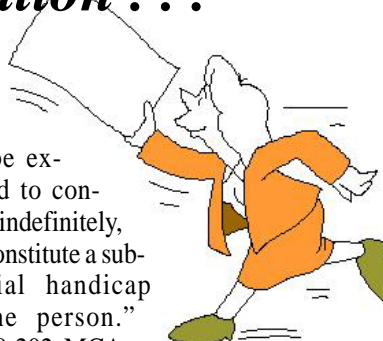
can be expected to continue indefinitely, and constitute a substantial handicap of the person." (53-20-202, MCA., 1979)

If you're still thirsty, you might slake it on-line at: Developmental Behavioral Pediatrics Online Community <http://www.dbpeds.org/usf/conditions/articles/devdis.html>. Or for more information about developmental disabilities and the services available, contact the Montana Developmental Disabilities Program at (406) 444-2591 and/or the Montana Developmental Disabilities Planning and Advisory Council at (406) 444-1334.

Yours in the ongoing quest,  
Professor Penelope Prevention

*If you have a question for the dear professor, please send it to:*

Professor Prevention  
C/O The Prevention Resource Center  
P.O. Box 4210  
Helena, Montana 59604



## The Way We Really Are

*Continued from page 18*

relying so heavily on people's resiliency that we discount the importance of social support programs.

In the final chapter of her book, Coontz outlines what she believes today's families really need:

- high-quality, well-regulated, affordable child care and education;
- an expanded tax allowance for children that keeps up with inflation;
- family-friendly work policies, including paid parental leaves;
- job creation and job training for those under economic stress;
- high school programs on child development;

- expanded opportunities for youth through which they can have meaningful roles in our society;
- well-designed mentoring programs that offer every child a relationship with a caring adult outside the home; and
- giving kids a second chance to succeed.

Getting rid of what doesn't work and expanding the programs that do won't be cheap. But the issue, according to Coontz, comes down not to whether we have the money to help America's families but whether we have the values to do so. One thing's for sure: we will never solve our problems by clinging to an idealized belief in a family that never existed.  $\Delta$

—Book Review by Kirk Astroth, Ph.D.

## The Costs and Causes of Traumatic Brain Injury

EVERY 15 SECONDS, ONE PERSON IN THE U.S. SUSTAINS A BRAIN INJURY

- An estimated 5.3 million Americans—a little more than 2% of the U.S. population—currently live with disabilities resulting from brain injury.
- It is estimated that one million people are treated for TBI and released from hospital emergency rooms every year.
- Each year, 80,000 Americans experience the onset of long-term disability following TBI.
- Vehicle crashes are the leading cause of brain injury, accounting for 50% of all TBIs.
- The risk of TBI is highest among adolescents, young adults and those older than 75.6

### The Cost

The cost of traumatic brain injury in the United States is estimated to be \$48.3 billion annually. Hospitalization accounts for \$31.7 billion, and fatal brain injuries cost the nation \$16.6 billion each year.

<<http://www.biausa.org/index.htm>>

# RESOURCE LIST

**ADA Information Center**

[www.ada.infonet@mtc-inc.com](http://www.ada.infonet@mtc-inc.com)

**American Foundation for the Blind**

<http://www.afb.org>

**Americans with Disabilities Act Document Center**

<http://janweb.lcdi.wvu.edu/kinder/>

**Deaf World Web**

<http://dww.deafworldweb.org> (or)  
[dww.org](http://dww.org)

**Disability Information and Resources**

[www.Eskimo.com/~jlubin/disabled.html](http://www.Eskimo.com/~jlubin/disabled.html)

**EASI's K-12 Educational Technology Center**

<http://www.rit.edu/~easi/ak12/k12.html>

**Epilepsy Foundation of America**

Web Address: <http://www.efa.org>  
4351 Garden City Drive, Suite 406  
Landover, MD 20785  
301-459-3700  
(800)332-1000;  
(800) 332-2070 (TTY)

**Equal Employment Opportunity Commission**

<http://www.eeoc.gov>

**Family Village Community Center**

<http://www.familyvillage.wisc.edu/center.htm>

**Job Accommodation Network**

<http://janweb.icdi.wvu.edu/English/homeus.htm>

**KidsHealth**

<http://kidshealth.org/>

**LD OnLine**

<http://www.ldonline.org/>

**National Attention Deficit Disorder Association**

<http://www.add.org/>

**National Center for Learning Disabilities**

<http://www.nclld.org/>

**Parenting Q&A**

<http://www.parenting-qa.com/>

**Presidents' Committee on Employment of People with Disabilities**

<http://pcepd.gov>

**Teaching Strategies, Inc.**

<http://www.teachingstrategies.com/>

**The Access Board**

[www.access-board.gov/](http://www.access-board.gov/)

**US Department of Justice ADA Homepage**

[www.usdog.gov/crt/ada/adahoml.htm](http://www.usdog.gov/crt/ada/adahoml.htm)

**Virtual Children's Hospital**

<http://vch.vh.org/>

Books and Guides are also available on loan from the Montana Center on Disabilities or Parents Let's Unite for Kids (PLUK). For a catalog, contact The Rural Institute on Disabilities: 1-888-648-7267 or The Montana Center on Disabilities: 1-406-657-2072.

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